THE USE OF OUTCOME MEASURES WITH CHILDREN/YOUNG PEOPLE WITH MORE SEVERE LEARNING DISABILITIES:

Sharing our experiences of what works in practice

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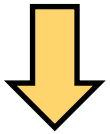
Current situation

Limited, largely anecdotal evidence of measures to use

Range of services operating in isolation



Lack of consensus

(Pote & Goodban, 2007)

Some specific issues

- Complexity and diversity of needs of CYP with learning disabilities *(Yates, et al, 1999)*
- Learning is likely to be slower
- Acquiescence
- Heterogeneity

Towards a consensus

STEP 1:

Initial survey of BPS Division of Clinical Psychology (DCP) Faculty for Children, Young People and their Families LD Network

- identifying measures used
- experience of using them in practice

STEP 2:

Publication of articles to stimulate discussion

(Rossiter et al, 2013; Phillips et al, 2014)

STEP 3:

Replication of evaluation project for adults with learning disabilities whose behaviour challenges services by BPS DCP Faculty for Learning Disabilities *(Morris et al, 2012)*

Findings from initial survey: What do we use?

BEHAVIOUR/ MENTAL HEALTH	Strengths and Difficulties Questionnaire (SDQ)
	Nisonger Child Behavioural Rating Form (N-CBRF)
	Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD)
	Developmental Behavioural Checklist (DBC)
	The Behaviour Problems Inventory (BPI-01)
ADAPTIVE FUNCTIONING	Developmental Disabilities - Children's Global Assessment Scale (DD-CGAS)
	Vineland-II
	Adaptive Behaviour Assessment System (ABAS-II)
SYSTEMIC	Sheffield Learning Disability Outcome Measure (SLDOM)
	Parenting Stress Index (PSI)
	Family Quality of Life Scale (FQOL)
	Challenging Behaviour Attributions Scale (CHABA)
	The Emotional Response to Challenging Behavior Scale (ERCBS)
	CHI-Experience of Service Questionnaire (CHI-ESQ)
OTHER	Goal-based Outcome measures
	Session by Session measures

Findings from initial survey

Generally

- Recommended outcome measures for CYP generally are not always appropriate
- Need to capture individual and systemic change
- Need to measure quality of life/adaptive functioning as well as behaviour change

Findings from initial survey

Clinical usefulness

- Full extent of the needs of this group of CYP captured?
- Sensitive to change?
- Ease of use?
- Norm-reference group?

Step 3: Replicating adult survey

- Interest group formed consisting of interested professionals working in CYP learning disability services

- Development of survey based on outcome measures already in use (identified in Step 1) and based on the adult learning disability study *(Morris et al, 2012).*

- Dissemination of survey through local Special Interest Groups and the DCP CYP Learning Disability Network

Survey questions

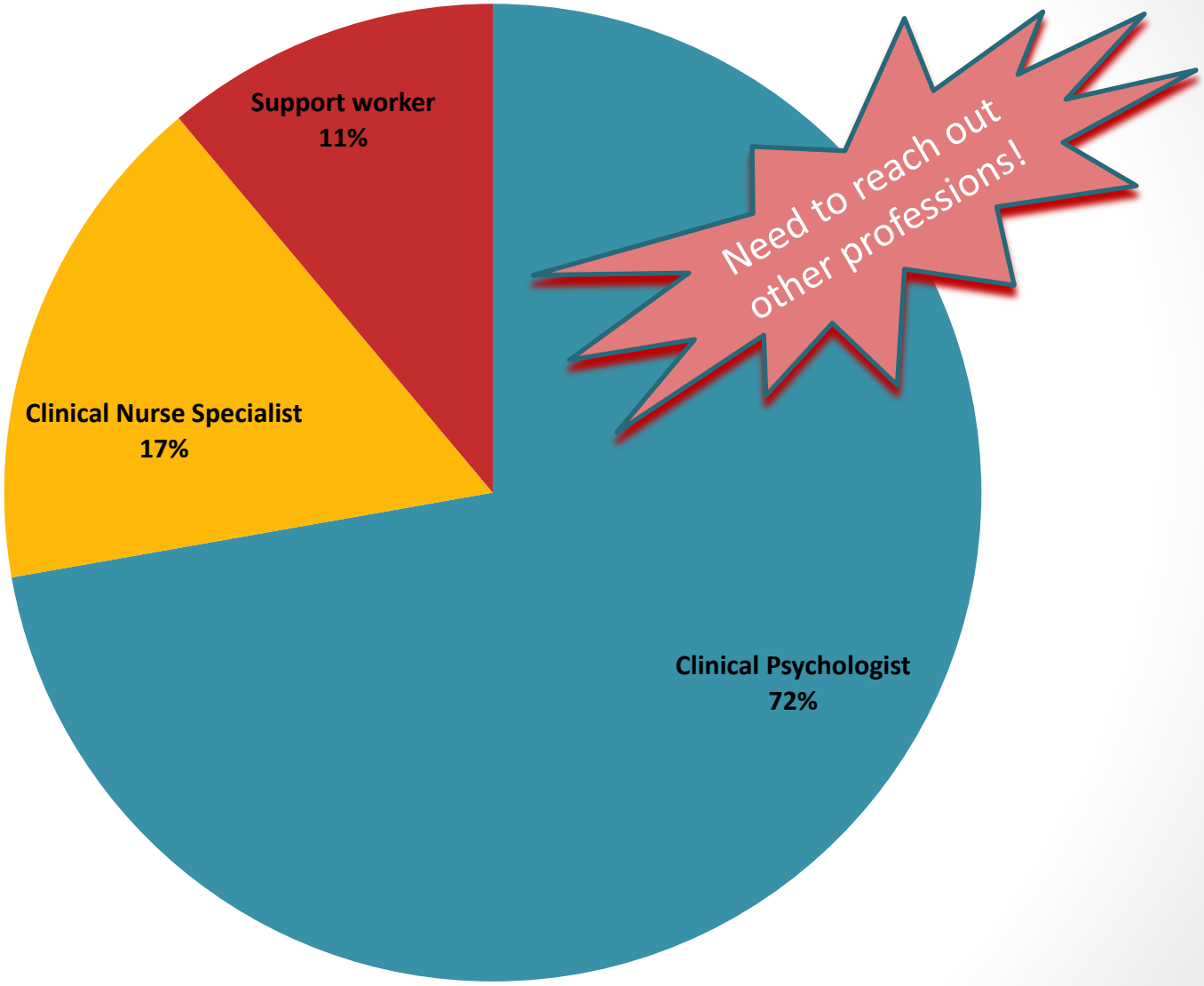
- Do you use this measure with families with children with LD?
- If so, do you find it useful?
- Do you think respondents find it useful?
- Do you think respondents (carer and/or clinician) find it easy to complete?
- Do you use it as an outcome measure to detect change?
- Describe the main advantages/disadvantages of this measure
- **Do you use any other measures?**

Preliminary results

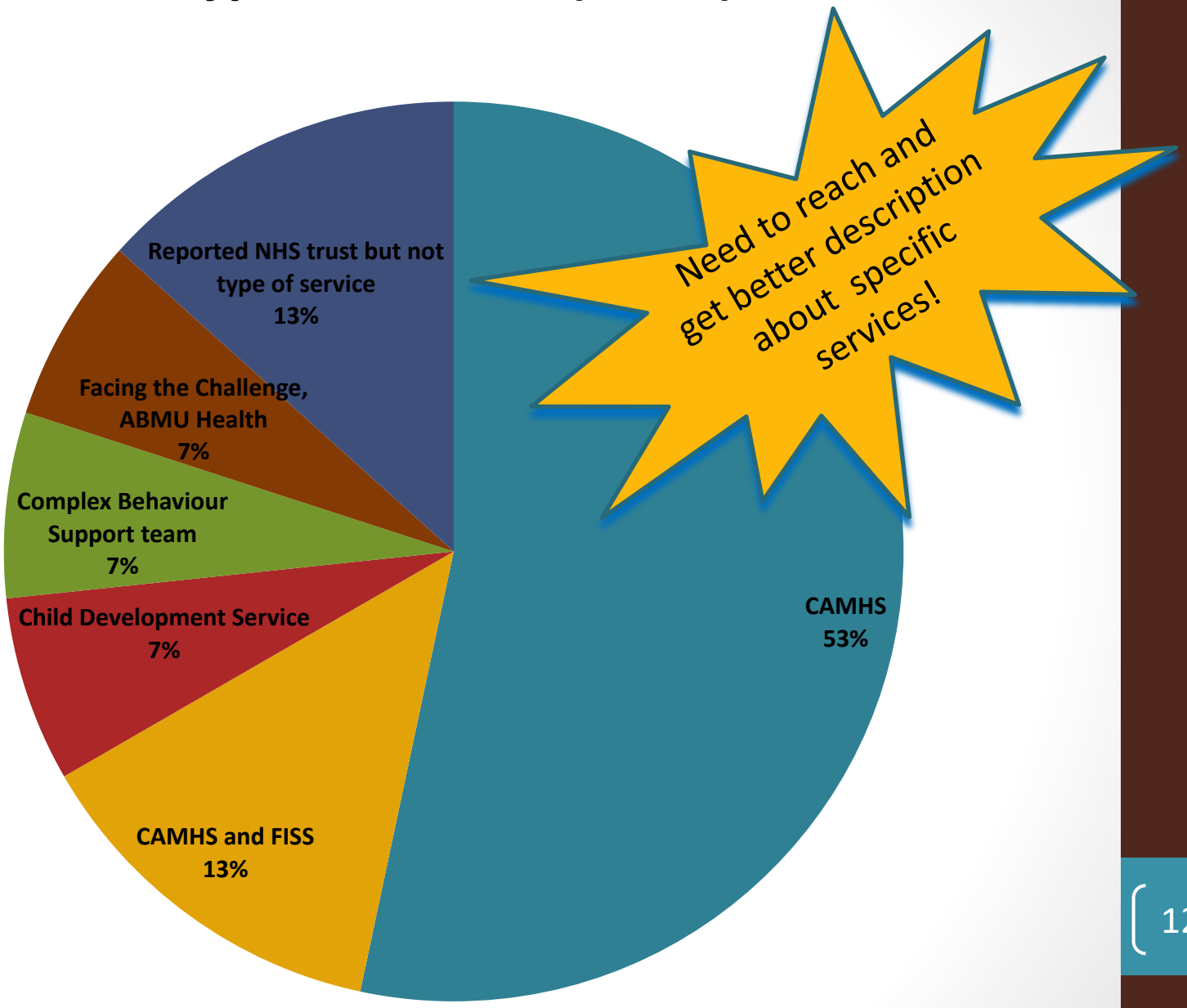
- Demographics
  - N = 49
  - But only N = 19 gave their details

Only asked for details to those interested in taking part in bigger project!

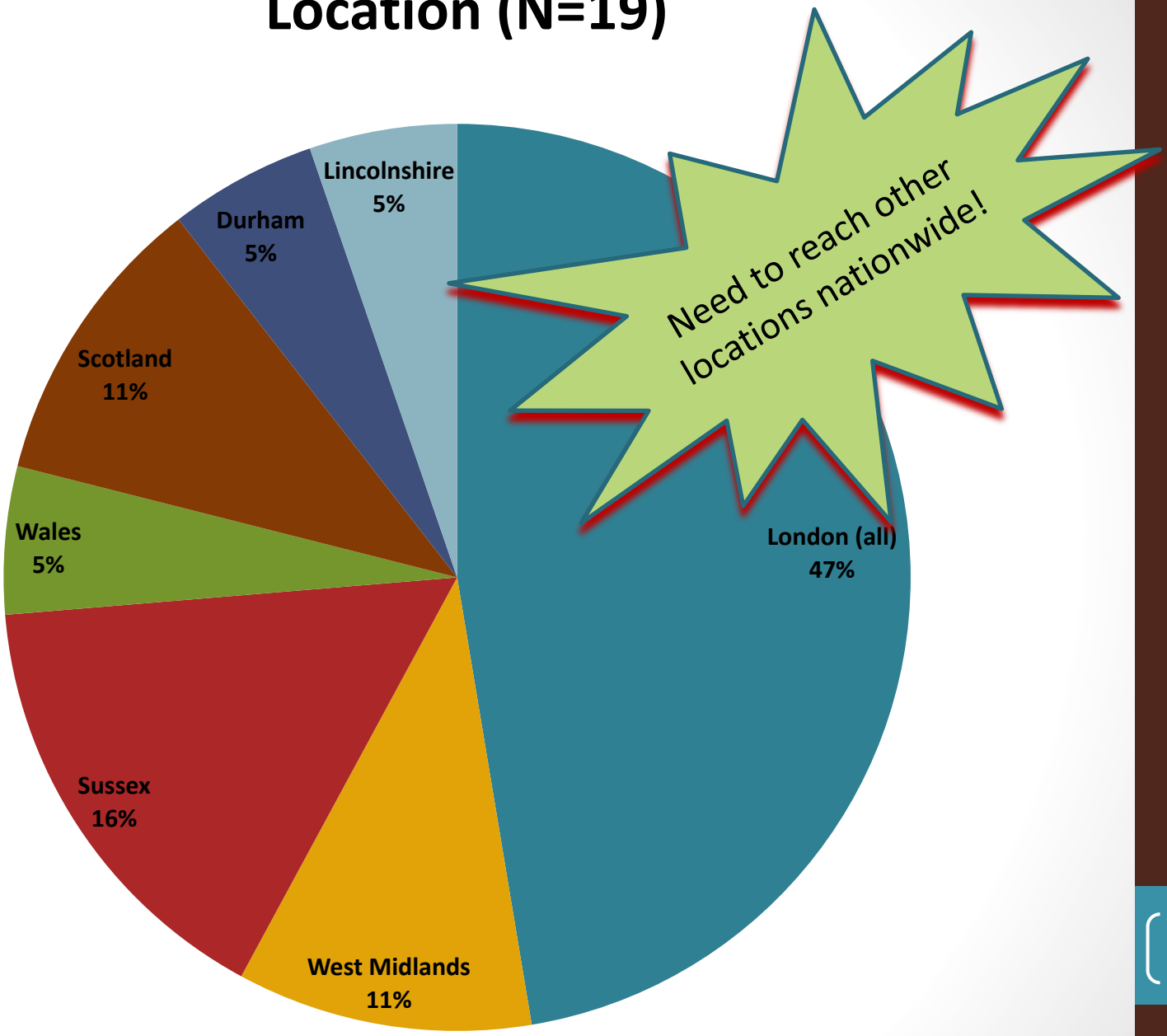
Profession (N = 19)



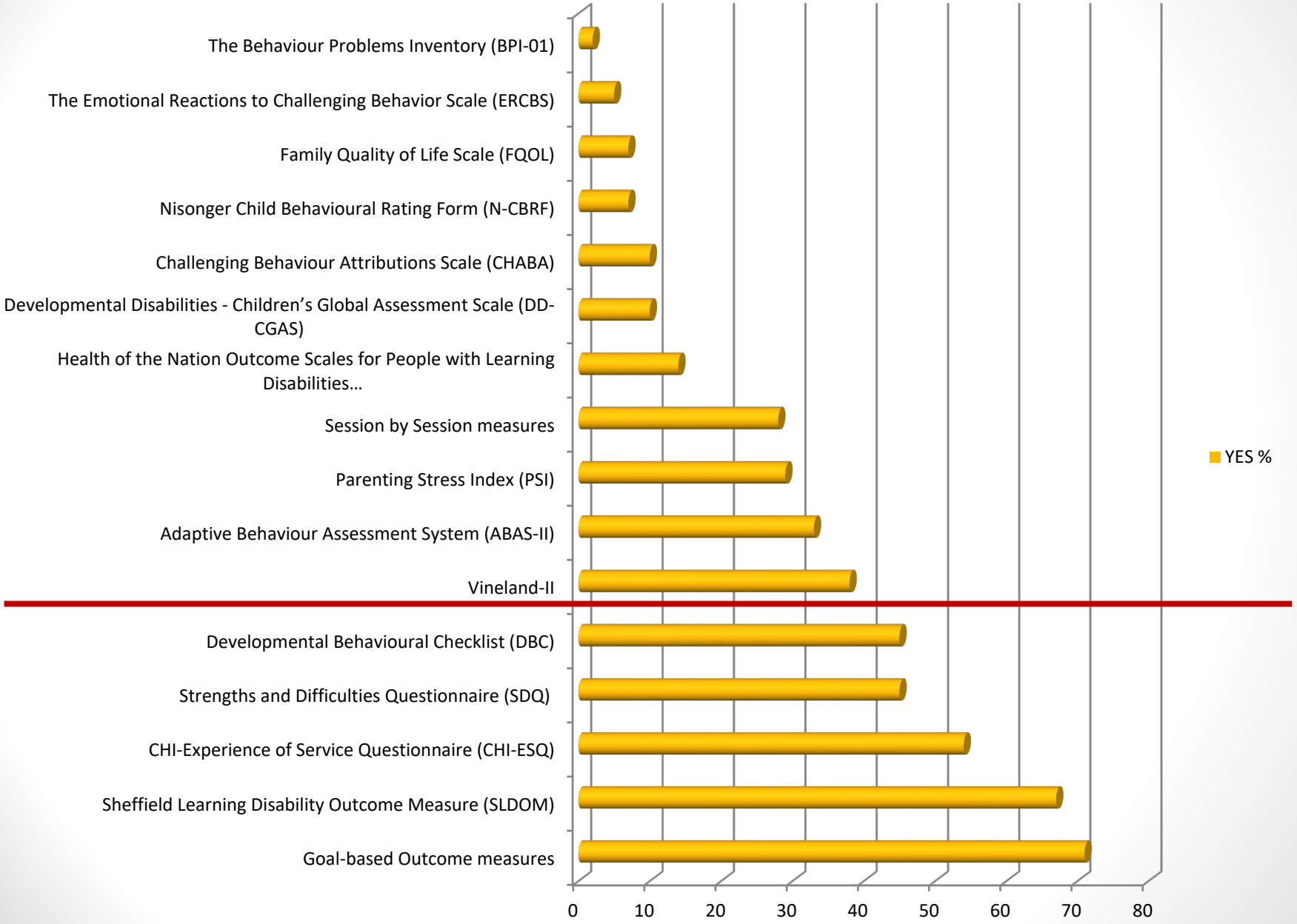
Type of Service (N=15)



Location (N=19)



Do you use this measure with families with children with LD?



Specific answers

	Useful clinically? %	Parents find it useful? %	Easy to complete? %
Goals-based	97	90	87
SLDOM	93	66	79
CHI-ESQ	96	90	91
SDQ	80	45	70
DBC	90	60	61

Advantages/Disadvantages

Measure	Advantages	Disadvantages
Goal-based Outcome measures	Measures change Highlights parent/carers main concerns Reflective Relevant and specific	Goals may change over time Skill to collaboratively set
SLDOM	Considers parents feelings Easy and quick Can measure change	Positive and negative q's can be confusing No overall score
CHI-ESQ	Quick and easy Good way to get feedback Qualitative, meaningful data	Difficult to complete for LD children
SDQ	Ease of use Covers range of CAMH concers Useful to look at impact of service Measures change	Doesn't monitor change Not appropriate for LD Engagement Designed for commisioners Difficult for parents to complete Relevance for younger children Limited How q's are worded (ambiguous)
DBC	Useful - measures change Easy and clear to complete Appropriate and relevant for LD	Lengthy Difficult to complete - English not 1st language Cost

Other measures reported

Name of outcome measure	Reported by no of services
Aberrant behaviour Checklist	1
Behaviour grids to measure parental perceptions of difficulties	2
Checklist of Challenging Behaviour and Rating Scales	1
Complex Sleep disturbance index	1
Conners	1
Considering a skills questionnaire such as "Essentials for Living"	1
Current View	1
HADS for parental mental health	1
Honosca	1
Paddington Complexity Scale.	1
Parenting competence scale	1
Parents top 3 concerns	3
PedsQOL battery	1
Questionnaire on Resources and Stress.	1
RCADS for IAPT	1
Service developed satisfaction questionnaire	1
Sleep specific measures	1
Social communication questionnaire	1

Conclusions

Need a package of measures – individual and systemic.

On the basis of the preliminary information the survey would seem to suggest that the outcome measures to use are:

- Focus of work:
  - Goals-based outcome measure
- Parenting competence/understanding/confidence:
  - SLDOM
- Behavioural/emotional needs of child:
  - DBC
- Satisfaction:
  - CHI-ESQ

Conclusions

- However, need to:
  - Reach out to other services, type of professionals and locations.
  - Evaluate effectiveness of OM more systematically (pre and post intervention?, service user feedback?).
  - In line with IAPT principles.
  - Look at other measures that are not commonly used but have been rated as being useful.
  - Need to develop new measures?

References

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